

Perspectives on Help Received from the Centers for Independent Living by Persons with Chemical Sensitivities

Identification of Investigators & Purpose of Study

Dr. Pam Gibson of James Madison University is seeking persons with chemical sensitivities who have requested help from a Center for Independent Living (CIL) to participate in a research study. The purpose of this study is to examine your perspective on the help you received from your Center for Independent Living (CIL) and to gather input from persons with chemical sensitivities regarding the kind of help they need from these centers.

Research Procedures

This study consists of an online survey that will be administered to individual participants through WebSurveyor. The survey can be accessed by clicking on the link below. The link is also accessible through Dr. Gibson's MCS website at <http://www.mcsresearch.net>. You will be asked to answer questions about services you have requested from a CIL, help you have been given, and ways that you could be better served. **YOU MAY ALSO PRINT OUT AND COMPLETE THIS HARD COPY AND RETURN IT TO US BY MAIL.**

Time Required

Participation in this study will require 20–30 minutes of your time.

Risks

We do not perceive more than minimal risks from your involvement in this study.

Benefits

Potential benefits from participation in this study include helping Dr. Pam Gibson gain a better understanding of the help provided to persons with MCS by the CILs, as well as having the opportunity to give input that may help to improve these services.

Confidentiality

The results of this research will be submitted to conferences and possibly to journals for publication. Individual responses are anonymously obtained and recorded online through a secure online survey tool; data are kept in the strictest confidence. Aggregate data will be presented representing averages or generalizations about the responses as a whole. All data will be stored in a secure location accessible only to the researcher.

Participation & Withdrawal

Your participation is entirely voluntary. You are free to choose not to participate. Should you choose to participate, you can withdraw at any time without consequences of any kind.

Questions about the Study

If you have questions or concerns during the time of your participation in this study, or after its completion or you would like to receive a copy of the final aggregate results of this study, please contact Dr. Gibson. Also if you or someone you know would like to participate, but is unable to do so online, please contact us to either schedule a phone interview or to receive a hard copy of the survey.

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Questions about Your Rights as a Research Subject

David Cockley, Ph.D.
Chair, Institutional Review Board
James Madison University
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DEMOGRAPHICS: PLEASE CIRCLE THE CORRECT ANSWER IN THE FOLLOWING QUESTIONS.

1. Gender:

- Male
- Female

2. What is your age (in years): _____

3. What is your racial background:

- African American
- Latin American
- Native American
- Caucasian
- Asian American
- Pacific Islander
- Other

4. What is your highest level of education completed:

- Some high school
- High school degree
- Associate's degree
- Technical certificate
- Bachelor's degree
- Master's degree
- Doctoral degree

5. How long have you been experiencing the symptoms of MCS?

6. Please use the following scale to assess how severe your symptoms are?

1. MILD: Able to work. Frequently has many symptoms, some of vague nature. May find petrochemicals and other environmental exposures such as auto exhausts cigarette smoke, and cleaning materials to be unpleasant or produce uncomfortable feelings but able to work effectively.

2. MODERATE: Able to work at home or with controlled environment at work place. May have to use gas mask or charcoal mask and air purifier filter system. Exposure to inciting agents causes acute symptoms which may alter functional capacity (severe headache, muscle pain, poor concentration, memory loss, etc.). May have to change job or work conditions if environmental pollution is severe enough.

3. SEVERE: Unable to work effectively, even with environmental control, using avoidance, masks or filters. On some days, may be able to work 30 to 60 minute shifts several times a day if in a very controlled environment. Reacts to chemicals such as insecticide, phenols, chlorine, formaldehyde, perfume, petro-chemicals, etc. Has severe mental and physical symptoms which may or may not clear. Public exposures such as church, post office, movie or shopping are not tolerated. Visitors to home must clean up significantly. Can usually care for self in a home situation. May be able to drive if automobile made free of inciting agents, sealed, and has charcoal air filters. Has difficulty with other family members or guests in home who bring in aggravating exposures on clothing, printed material, hair, etc. Adversely

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reacts to many medications. May have to move if existing home has uncontrollable outdoor pollution, is new and has not outgassed, or has other significant problems of mold, flooring, or other incitants. Requires a clean room, carpet-free, cleared of inciting agents, special heating and air filtering. Must wear natural fiber clothing specially laundered.

4. TOTALLY DISABLED: Requires assistance to function in rigidly controlled home environment. Reactive symptoms have spread to virtually all environmental agents including chemicals, foods, pollens, and molds. Has mental and physical symptoms that are incapacitating, although frequently not structurally described. Total and very restrictive environmental control required in home and vehicle. Cannot tolerate family or help who have outside exposures with even small Contamination of clothing or hair with odors. Visitors usually are too toxic to be tolerated indoors. Usually requires several moves to different areas of the country to find tolerable climate which is also chemical free. May require unusual and extensive measures to make a tolerable clean refuge area to sleep in. Has difficulties with virtually everything in environment (universal reactor).

7. Are you currently employed?

Yes

No

8. If not, is MCS a factor in your unemployment?

Yes

No

Please Explain:

9. What are your current living conditions?

-own a house

-rent a house

-live with relatives or friends

-live in a nonpermanent fixture such as a car, recreational vehicle, or tent

- other (please specify)

10. Have you ever applied for worker's compensation?

Yes

No

11. Have you ever applied for Social Security Disability Insurance (SSDI)?

Yes

No

12. Are you familiar with the Centers for Independent Living (CILs)?

Yes

No

13. Have you ever asked a CIL for services in coping with MCS?

Yes

No

14. If not, can you tell us why not?

If you have requested services from an ILC, please answer the following questions.

15. If you did apply, did you get services?

- Yes
- No

16. Was the facility (or part of it) accessible/safe for you?

- Yes
- No

17. Was the staff member who worked with you familiar with MCS?

- Yes
- No

18. Was the staff member who worked with you scented?

- Yes
- No

19. Did you request accommodations in regard to the visit?

- Yes
- No

20. If you asked for accommodations for the visit, what did you request?

21. Did the ILC meet your accommodation requests for the visit?

- Yes
- No

22. If so, how did they accommodate you for the visit?

23. What kinds of help did you request from the ILC?

24. Did you receive help with any of these requests?

Yes

No

25. Please explain what help you received.

26. Did you feel that the ILC's response was reasonable with regard to your disability and disability status?

Yes

No

27. If you answered "no" to the previous question, can you tell us why not?

28. Please explain and describe anything else about your ILC experience that you would like us to know.

We are now interested in greater detail about any services you received. Please answer the following questions about specific services that you might have received from a CIL.

29. Did a CIL help you apply for disability benefits?

Yes

No

If so, please explain how:

30. Did a CIL help you apply for work compensation?

Yes

No

If so, please explain how:

31. Did a CIL help you to find low-income housing?

Yes

No

If so, please explain how:

32. Did a CIL help you make your home safer for your chemical sensitivity?

Yes

No

If so, please explain how:

33. Did a CIL help you to set up self-employment?

Yes

No

If so, please explain how:

34. Did a CIL assist you with transportation to community or medical services?

Yes

No

If so, please explain how:

35. Did a CIL help you find counseling and/or support groups?

Yes

No

If so, please explain how:

36. Did a CIL help you pay for medical care?

Yes

No

If so, please explain how:

37. What would be the most beneficial kind of help that you could receive to cope with MCS?

38. If an educational program regarding MCS were to be offered to the CILs, what is the most important content that you would like to see included? (MORE SPACE ON BACK)

39. One last question: In what country did you ask for help from a CIL?

U.S.

Canada

Other - please specify _____

THANK YOU VERY MUCH FOR YOUR HELP IN COMPLETING THIS SURVEY! PLEASE PRINT OUT AND RETURN TO:

DR. PAM GIBSON
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HARRISONBURG, VA 22807

IF YOU HAVE ANY QUESTIONS, PLEASE E-MAIL ME AT gibsonpr@jmu.edu

WE WILL DO OUT BEST TO USE THIS DATA TO HELP PERSONS WITH MCS.